



January 10, 2020

NIMH Strategic Planning  
6001 Executive Boulevard, MSC 9663  
Bethesda, MD 20892-9663

**Re: Request for Information (RFI) on the 2020 National Institute of Mental Health (NIMH) Strategic Plan for Research (NOT-MH-20-003)**

Dear Dr. Gordon and Colleagues:

Thank you for the opportunity to provide feedback and comments on the National Institute of Mental Health (NIMH) 2020 Strategic Plan for Research.

Mental Health America (MHA) – founded in 1909 – is the nation's leading community-based nonprofit dedicated to addressing the needs of those living with mental illness and to promoting the overall mental health of all Americans. Our work is driven by our commitment to promote mental health as a critical part of overall wellness, including prevention services for all, early identification and intervention for those at risk, integrated care, services, and supports for those who need it, with recovery as the goal.

Consistent with this mission, we are writing for three reasons: to express our gratitude for NIMH's groundbreaking work to intervene early in psychosis; to applaud the continued focus on prevention and early intervention in the strategic plan; and to offer some suggestions for areas that could be strengthened and are particularly relevant for public health.

First, we write to express our gratitude for NIMH's work on early psychosis. Due to the findings of the RAISE initiative and subsequent policy development, over 10,000 young people and their families facing these very serious illnesses have had access to the highest quality care most likely to lead to positive outcomes. That is a far cry from where we were before this research when young adults and their families received no education or support as they addressed this serious condition.

We applaud and strongly underscore the need for continued funding and attention to the Early Psychosis Intervention Network (EPINET) program, the first program in mental health to create a "learning healthcare system" to improve quality of care. Other health conditions, such as cancer, have long had networks to share information and improve quality of care through research, but mental health has lagged. This effort is significant not only for enhancing our knowledge and treatment of early psychosis, but also for beginning a quality improvement effort that can be expanded to apply to other mental health conditions over time.

Second, MHA believes in preventing and intervening "before stage four" to address mental health conditions early as we do other health conditions. We strongly support and urge continued emphasis on research that will identify new paths for intervening with treatment and supports before a mental health condition develops, in childhood, or worsens.

Recognizing that we have not seen many major breakthroughs in mental health treatment and individuals and families continue to experience very difficult symptoms and outcomes, we

applaud NIMH's emphasis on genomic factors, neural circuitry and artificial intelligence to uncover novel mechanisms that can lead to radically new approaches. We will need new discoveries to prevent and cure these conditions. Doing more of the same will not lead to the change that is needed. With mortality increasing from mental health conditions, it is time to invest in working to discover structural, genomic and data driven factors that can be useful to prevention and cures. We further support the emphasis on developing behavioral or physical biomarkers which are needed for pharmaceutical companies to increase their investment in developing new treatments.

Third, we have the following suggestions to build upon the areas highlighted in the plan and provide information on areas that would have significant public health implications:

We urge additional attention to researching and developing validated instruments and quality measures in mental health that capture both clinical and functional improvement. The NIMH plan indicates a desire to impact public health. With CMS and health care payors moving to value based payment, it is critical that NIMH play a role in determining quality so value in mental healthcare is not solely defined by cost. It may be helpful to collaborate with the Centers for Disease Control and the Agency for Healthcare Research and Quality.

MHA has been participating in the American Psychiatric Association's efforts to define quality measures for mental health providers in anticipation of value-based Medicare incentives and the effort has been frustrated by the lack of validated instruments beyond those for depression. NIMH should conduct sufficient research to develop a specific, recognized tool for each of the mental health conditions or across conditions that measure clinical and functional efficacy and also indicate how much improvement should be expected.

For many of the projects in the strategic plan, NIMH notes a desire to measure outcomes, but without validated, consistent tools, there is no way to do that in a way that can be scaled and replicated in the real world of health systems. Individual researchers funded by NIMH develop the tools they will use to measure improvement for specific studies, but with healthcare moving to value based care, the mental health community needs validated tools that are widely accepted and used to measure whether the individual is getting better clinically and meeting their functional goals. For some illnesses, such as depression, clinical symptom abatement is indicative of increased functional ability. For others, such as psychosis, the side effects to medication can be substantial so understanding whether the individual is improving both clinically and functionally with respect to their ability to engage in school, work, relationships and other meaningful activities is important. Many individuals are interested in measuring their ability to achieve life goals but little research has been conducted to determine if there is a uniform and scalable way to do this given the other factors that affect the ability to work or go to school. NIMH should fund research to develop validated tools for measuring improvement and determining when treatment needs to be adjusted.

Next, we recommend a strong emphasis on researching the effectiveness of peer support. The Strategic Plan indicates continued efforts to test interventions that have practical relevance to increase the likelihood that the intervention is feasible and scalable. We strongly urge NIMH to focus on peer support services for this work. Such research would be very important for public policy given that Medicare and private insurance currently cover very little peer support and peer support specialists providing care in the Medicaid program are undervalued as reflected in their low wages. Such research should include:

- Validating the effectiveness of peer support specialists who are trained on the SAMHSA core competencies and have demonstrated experience and knowledge through certification, such as the National Certified Peer Specialist (NCPS) certification.
- Developing and testing existing and new implementation strategies for peer support specialists as parts of care teams across settings including primary care, emergency departments, criminal justice settings, inpatient services, outpatient services, and telehealth.
- Developing and testing innovative strategies for peer support services across the continuum of services, including hospital diversion programs such as peer-run respite care and early intervention programs for children, adolescents, and adults, especially for those experiencing early symptoms of mental illness.

MHA applauds the plan's emphasis on prevention and early intervention and strongly supports a greater focus and more specificity with respect to youth. Rates of depression and anxiety are precipitously increasing along with suicide rates for this population. The Congressional Black Caucus recently released a report to Congress noting that the suicide death rate for black youth is rising faster than any other racial group and also emphasizing that black adolescents are significantly less likely to receive care for depression, a risk factor for suicide.<sup>1</sup> The first recommendation of the report is to increase the amount of research into topics relating to black youth mental health and suicide through NIMH funding and the second recommendation is to increase funding and resources for black researchers focused on these topics. MHA strongly supports these and the other report recommendations and urges attention to these issues in the strategic plan.

We appreciate NIMH's recognition in the strategic plan of the need to test effective interventions in pediatric settings serving children, such as schools and primary care. We would specifically note that states are increasingly passing laws or administratively requiring K-12 mental health education (New York, Virginia, Texas, Florida). National research to determine which curriculum or school-based programs leads to better outcomes with respect to reducing rates of anxiety and depression as well as increasing early identification of psychosis and other illnesses would be helpful. It would also be helpful to research whether curriculum or other school initiatives contribute to school connectedness, which has also been shown to lead to better adult outcomes. Youth with mental health conditions have the highest drop out rates of any disability category, suggesting that further research on interventions that have strong school outcomes would be very helpful.

We also appreciate NIMH funding studies regarding the effect of digital based supports and social media on child and adolescent mental health and suggest increasing this work because of the widespread public health implications. Through our MHA Screening program, MHA has data from 4.7 million users across the country who take a mental screen on the MHA website and are seeking various forms of support online. Among screeners, approximately 2/3 are youth (11-17 years old) and young adults (18-25 years old). Nearly 50 percent of the total individuals screened want follow up mental health education, 46 percent want worksheets or materials they could use at home and 45 percent are interested in mobile or online tools. We applaud NIMH's interest in researching ways to engage and provide assistance to individuals, including through digital health. We appreciate NIMH's recent focus on increasing research on engagement and motivation strategies for early identification and intervention. We recommend funding research

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<sup>1</sup> "Ring the Alarm: The Crisis of Black Youth Suicide in America," A Report to Congress from the Congressional Black Caucus Emergency Task Force (2019).

on how to best engage, motivate, and obtain positive outcomes for individuals in a digital or online space as a priority area of focus. This is especially true given that most youth who are experiencing the earliest signs and symptoms of mental illness are seeking information and support online.

Other areas for further research include exploring elements of internet use that are particularly harmful or solutions to reduce risk or increase protective factors related to internet use. Social media companies are beginning to consider hiding “likes” and other methods of decreasing the negative consequences of social media, but strong research findings would be helpful to support the mental health of our youth, who are spending many hours engaging with social media. Based on our research of youth internet habits, MHA is concerned with the negative consequences of exposure to or priming towards violence and sexual content at a young age (3-12 years old) and the long term effects of high brain stimulation due to technology use from age 0-3. Research on the relationship between tobacco and cancer led to widespread public health efforts to reduce teen smoking and research on nutrition and school lunches has had a similar effect on obesity. It is time to thoroughly research the effect of internet and social media use on youth mental health.

Next, MHA would recommend that NIMH direct research funds to more information regarding how people use medication as a tool for recovery, particularly with respect to discontinuation of medication. Research indicates a high percentage of individuals newly diagnosed with bipolar disorder and schizophrenia will decide to discontinue medication for a variety of reasons. Some of those individuals will never have another episode and others rapidly get very ill with serious consequences such as involvement in the criminal justice system or homelessness. This decision often leads to tensions between individuals, family members and providers. NIMH should devote resources to determine who can successfully discontinue medications and how people can be carefully monitored while doing so to allow them to try to reduce or discontinue if that is their preference without risking terrible consequences. This can inform practice guidelines and educate peers, families and providers. This work could be very impactful on reducing the criminalization of mental illness and homelessness.

NIMH has increased its emphasis on funding research into effective practices to reduce suicide, particularly with respect to screening and brief interventions in emergency rooms and for those who are struggling with suicidal thoughts online. To have the maximum public health impact, NIMH should continue research with an emphasis on how emergency rooms can most easily and cost effectively adopt practices to ensure universal screening and follow up. The Joint Commission currently requires hospitals to conduct suicide screening for behavioral health patients. We understand that this limitation is based on concerns that emergency rooms are not equipped to provide the needed interventions once a person is screened and identified. Further research on implementation protocols in emergency rooms and standardization of practices could be very helpful in moving to universal screening.

Online, approximately 50 percent of MHA’s 500,000 annual screeners for depression report having thoughts of suicide. Most report thinking about death and suicide daily. MHA is aware of little to no research on what protocols to follow after implementing a suicide screen online and the most effective interventions to support people struggling with suicidal thoughts in an online space. The most frequently used protocols inform people to call the National Suicide Prevention Lifeline, or Crisis Text Line. Our research shows that some people will use these resources, but a majority will not. Asking people to call 911 or go to the emergency room is also not a viable solution for most people. We request NIMH fund additional research on what can be done to

support people who are having passive and active thoughts of death and suicide. The research should focus on interventions for people who are struggling with their symptoms online, who wish to remain anonymous, and are interested in digital-based supports.

We fully support NIMH's emphasis on promoting health equity for women and underserved populations. We note that additional research on safety of medications in pregnancy and maternal mental health are needed as well as a concerted effort to include diverse research participants and diverse researchers in all of NIMH funded activities. MHA has also seen disproportionate screening and indications of depression in LGBTQ persons, especially youth, and would recommend research as to the underlying causes and effective interventions. Moreover, as previously noted, there is a need for greater research in the disproportionate increase in suicidal behavior in African American youth.

Finally, we are very grateful for NIMH's focus on engaging stakeholders and appreciate the many meetings and communications to organizations representing peers and families. The Director and NIMH staff go to great lengths to communicate and speak at conferences and through social media and host regular stakeholder advisory meetings. As part of those efforts, we would recommend that NIMH consider developing future strategic plan documents that are written in more accessible language for public stakeholders, such as peers, families and policymakers.

We would welcome the opportunity to answer any questions or provide further detail with respect to any of these recommendations and can be contacted at the email address below. Thank you again for the opportunity to provide comments and for your thoughtful and impactful work.

Sincerely,

A handwritten signature in cursive script that reads "Mary Gilberti".

Mary Gilberti

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